

Enjoying the Arts: Expect the Unexpected

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Last fall, I participated in the annual Leadership Exchange in Arts and Disability (LEAD) Conference in Scottsdale, Arizona, hosted by the John F. Kennedy Center for the Performing Arts. It was a gathering of professionals who work in the performing arts, theatres, galleries and other creative venues. I participated in a workshop panel entitled, “Expect the Unexpected.”

The “unexpected” can be surprisingly rewarding. On a cold December day in 1956, I remember standing in line with my family at New York City’s Radio City Music Hall to see the Rockettes. An usher saw my difficulty in walking and ushered all of us to a side door ahead of a long line of customers. A similar incident happened at the 1964 New York World’s Fair when an usher guided my whole family (parents, siblings, aunts, uncles and cousins) out of line to view Michelangelo’s “Pieta” from a quiet side room. I was using a wheelchair.

I have limb-girdle muscular dystrophy, and, in 1988, had respiratory failure caused by a flu bug or pneumonia and weak diaphragm muscles. As a result, I was trached. In 1995, I switched to noninvasive ventilation using an exsufflation (pneumobelt) belt (Respironics, Inc.) and various mouthpieces. Over the years, I have used different ventilators and currently use the LTV®950 (Pulmonetic Systems) because it is compact, lightweight and fits my active lifestyle. Recently, I retired after 30 years in higher education and am presently consulting and grantwriting.

As a child, my mother, a professional cellist, took me to concerts, and I literally grew up backstage meeting the famous performers of the 1950s and 1960s. This instilled a love of classical music, symphony, theatre and the arts, and I love being “on-the-go.”

During the last eighteen years, my attendance at concerts by string quartets, soloists and small music ensembles has generated a few unusual experiences. There’s no escaping the similarity to Darth Vader as the ventilator

inhales with a baritone whoosh and exhales in a swish. Most users are accustomed to the sound and tune it out. However, it is annoying to some people in an audience who can’t dismiss the repetitive sounds.

About five years ago, during a solo musician’s performance at a university theatre, a fellow patron of the arts stood up during intermission, turned around, pointed a long, bony finger at me in the back of the auditorium, and said loudly, “YOU should not be allowed in this theatre!” Gasps and indignant comments were heard all across the audience. Out in the hallway, I was surrounded by sympathetic music students who insisted that I stay for the rest of the concert. I did, but sat between two sets of closed entrance doors where I could hear the music, but where my ventilator was muffled. A large group of students sat on the floor around me.

The following week, the Dean of the Music College called to apologize and asked if I would work with his staff to find a way to ensure the comfort of

all patrons who attended concerts. We looked into numerous options including access to the mechanical room at the back of the auditorium where I could view the performance on a small TV screen and listen through speakers. We explored ways to muffle the ventilator's sounds with padded covers which, unfortunately, caused it to overheat.

A similar incident involved a larger theatre and a visiting string quartet. In this case, the wheelchair accessible seating was level with and close to the stage with a low carpeted wall behind the area which should have been a nice sound barrier. Not so! During the first half of the performance, the musicians kept looking around the room in annoyance. After intermission, before they started playing, the first violinist apologized for the extremely bad acoustics and noisy air-conditioning system in the brand new, state-of-the-art building. I realized he was hearing the breathing of my ventilator as it reflected off the wall behind me.

Over the years, acceptance has been more common than rejection. I've attended Broadway productions, concerts, symphonies and small music ensembles in a variety of theatre settings without any complaints from the audience or the performers.

I steer clear of recitals with one or two performers in small recital halls and select 'noisy' musical performances in medium-sized venues. I've never had any additional complaints and no one (with any authority) has ever asked me to leave a concert.

One of the most memorable concerts was a solo performance by world famous violinist, Itzhak Perlman, at

LEAD invited representatives from IVUN to participate in a focus group with managers of venues around the country to discuss ways to assure unfettered access to plays, symphonies, etc., for users of home mechanical ventilation. Quiet is expected but some patrons are disturbed by the sound of portable ventilators. The group discussed the following.

- Most often patrons who complain about the "noise" are satisfied when given an explanation, i.e., "the lady uses a ventilator because she has ALS."
- Venues have a policy about the unacceptability of noise from cell phones, loud talking, etc. This policy should be expanded to include an explanation as to what noise is acceptable.
- Most ventilator users are conscientious patrons and are willing to work with management by calling ahead, helping to find the "best" seat, etc.
- Some ventilator users think their ventilator is distracting and do not even attempt to go to places that expect quiet.
- Under no circumstances should any alterations of a "noisy" device be made, because it is medical equipment that has been prescribed by a physician.
- In most cases, managers of venues change the seats of the complaining patrons. However, this can be very difficult if there is a full house.

Other suggestions include:

- Offer the person who complains the opportunity to wear an Assistive Listening Device (ALD) to block out environmental noise and improve his/her audio.
- Provide ventilator users with a closed room with sound piped-in and a large viewing window similar to space provided in some churches for families with small children.
- Provide a sound-proof box just for the ventilator. Is this possible with the need for air and the accumulation of heat?

the Frank Lloyd Wright Gammage Auditorium in Tempe. Mr. Perlman invited a group of Arizona State University students and staff with disabilities to sit on the stage while he played. Thrilled, I sat in my wheelchair with the ventilator puffing steadily ... not more than ten feet behind him. Afterwards, he spent two hours individually greeting us.

In any situation, a positive attitude, a sense of humor and flexibility are the keys to acceptance and coping with the unexpected. The surprises and rewards are beyond one's expectations.

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Enjoying the Arts: International Experiences

Sheila Keogh, Toronto, Canada

“My husband and I attend theatre and concerts on a fairly regularly basis. I take my PLV®-100 and have never encountered a complaint from anyone. I just wheel it in on a small luggage carrier and tuck it behind my wheelchair and say nothing. I run the tube under my clothing so it is fairly hidden except for a little piece of tubing holding the mouthpiece near my face. (I use an off-the-shelf mouthpiece from Medigas and when they told me they couldn't get them anymore, I bought up the last box of 14.) My vent is quite quiet except for the odd beep from the low pressure.”

Shoshanna Fahima, Tel Aviv, Israel

“I sing in an all women's choir while using a ventilator. The only comments I hear are 'keep up the good work' and 'more power to you.' I use ResMed's Mirage® Swift nasal pillows and the VPAP® III ST-A when I sing.”

John R. McFarlane, Senior Partner, McCON Services (consultants on disability and occupational health), Ireland

“The real question is whether the person in the wheelchair can access the auditorium in the first place. Unlike the Americans with Disabilities Act (ADA) in the United States, there is no equivalent for privately owned buildings in Ireland. The disability legislation that was passed here in 2005 only placed duty on publicly, i.e. state-owned facilities and then not for another 10+ years. There have been incidents in the last four years (until an Equality Bill came into force covering gender, race, age, disability) of people in wheelchairs being turned away because they constituted the old hoary one of 'a fire hazard.'

“Now the owners have the right to refuse entrance to anyone they believe could cause a disturbance. I have trawled through all my contacts here regarding ventilator use, and can find no case where entry has been refused or complaint made. Whether that is because no one has tried or not, I do not know.

“I have spoken with several theatres and the National Concert Hall, and their attitude was, 'No problem, but could we have prior notice by the ventilator user so we can ensure their comfort and enjoyment of the event?' I was also asked in one instance if the person would need a secure power supply in case of electrical failure or need a backup unit.”

Enjoying the Arts: Your Suggestions

Managers of venues in the US have asked ventilator users for their additional comments and suggestions. Please forward them to Betty Siegel, Director of Accessibility, The John F Kennedy Center for the Performing Arts (access@kennedy-center.org).

Siegel is looking for a ventilator user in the DC area who would be interested in serving on a panel during the 2006 LEAD conference, which will be held August 4-6 at the Kennedy Center in Washington, DC. (www.kennedy-center.org/accessibility; 202-416-8727) ▲